DOCUMENT RESUME

ED 267 564 EC 182 085

AUTHOR	Board, Mary Ann; And Others
TITLE	A Guide for the Personal Care Attendant: Independent Living with Attendant Care.
INSTITUTION	Institute for Rehabilitation and Research, Houston, TX.
SPONS AGENCY	Rehabilitation Services Administration (DHEW), Washington, D.C.
PUB DATE	80
GRANT	13P57889/6-02
NOTE	27p.; For related documents, see EC 182 086-087.
AVAILABLE FROM	Institute for Rehabilitation and Research, 1333 Moursund Ave., Houston, TX 77030 ($3.50 each; $10.50 set).
PUB TYPE	Guides - Non-Classroom Use (055)
EDRS PRICE	MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	*Attendants; Employment Opportunities; *Home Health Aides; *Individual Power; *Personal Autonomy; *Severe Disabilities

ABSTRACT

The first of three booklets on attendant care of severely disabled persons is addressed to the personal care attendants (PCAs). An introductory section reviews the basic concepts of independent living, noting the role of PCAs in promoting independence. Discussions of congenital and acquired disability are followed by information on equipment and devices and types of attendant care systems (private attendant systems and shared attendant services). Suggestions are offered for looking for and interviewing for jobs as PCAs. Additional information touches on training and the relationship between the PCA and the handicapped person (noting disability and attendant character types). Appended material includes a glossary and a list of resources. (CL)

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INDEPENDENT LIVING WITH ATTENDANT CARE:

A Guide for the Personal Care Attendant

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The **New Options** project was supported in part by a Research and Demonstration Grant 13P57889/6-02 from the Rehabilitation Services Administration, DHEW. Additional grant funds were also received from Research and Training Center 4, RSA, DHEW. However, the contents of this publication are solely the responsibility of The Institute for Rehabilitation and Research and are in no way the responsibility of the Rehabilitation Services Administration, DHEW.

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Printed in the United States of America.

designed by
Medical Illustration and Audiovisual Education
Baylor College of Medicine
Texas Medical Center
Houston, Texas 77030

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ACKNOWLEDGMENTS

The concepts presented in this booklet are the results of three years of experience (1976-1979) in the New Options Transitional Living Project at The Institute for Rehabilitation and Research, Houston, Texas. The Attendant Management Module taught by handicapped people (staff associates) to New Options participants generated many ideas and illustrations used in this text. The attendant system at New Options offered practical experiences in communication and problem-solving skills to both participants and staff attendants. Thanks to staff associates, participants, and attendants for sharing ideas, anecdotes, experiences, and skills.

The authors would also like to thank the many disabled people who were interviewed in preparation for this publication. Their willingness to discuss issues surrounding their own attendant care plus their enthusiastic support of this project indicated the need for printed information about this subject.

Another thank-you goes to the professional staff at The Institute for Rehabilitation and Research and the Texas Rehabilitation Commission who reviewed the material before its final revision. Their comments reflected thoughtful consideration of the ideas and illustrations presented.

Special thanks to Evelyn Lowdermilk for typing the material in the midst of other responsibilities.

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INDEPENDENT LIVING WITH ATTENDANT CARE: A Guide For The Personal Care Attendant

The job, personal care attendant (PCA) for handicapped people, is not new. Parents have been doing this job for years for their disabled children; husbands and wives care for their mates when they are ill or disabled; and nurses and nurses' aides care for their patients when they are not able to care for themselves. For the individual with a permanent disability, however, there are times when a personal care attendant who is not a family member or a nurse better meets this person's needs. There are several reasons for wanting to disengage from traditional kinds of physical care providers. One reason is that disabled people need to feel that they are in control of their lives. When family members provide their care, the handicapped person often feels that he has nothing to say about how that care is given; even as an adult, the disabled person may still feel like a child when his family "takes care of him." People with medical training such as nurses or nurses' aides often perform tasks in a specific, "cookbook" manner, again with no input from the person who is receiving the care.

The new independent living movement has redefined the job of personal care attendant (PCA). An attendant is someone who assists a handicapped individual with activities of daily living. This assistance enables the disabled person to participate fully in all aspects of "normal" life. The handicapped person might live alone, with a roommate, with family, or with or near a group of other handicapped people with similar needs. The important distinction that separates independent living from a dependent environment is that the handicapped person directs his own life, makes his own decisions, and is generally responsible for his own affairs. In a dependent environment, on the other hand, someone else tells the handicapped person what to do and when to do it. To illustrate:

Dependent Environment

1) The physical care provider performs tasks in a certain way with no input from the person receiving the care.

2) The disabled person is told when and how to do things, such as when to get up, when to go to bed, when to take medications, when to shower, etc.

3) The disabled person makes no decisions on his own and has no responsibility or control over his own life.

4) The disabled person simply exists.

Independent Living Environment

1) The personal care attendant (PCA) performs tasks according to directions from the disabled person receiving the care.

2) The disabled person decides when to get up, when to go to bed, when to shower, etc., and takes responsibility for taking his own medications on time.

3) The disabled person controls his own life through the decisions he makes; the disabled person is responsible for the consequences of his decisions.

4) The disabled person participates fully in life.

Your interest in the job, Personal Care Attendant (PCA), indicates that you have a desire to help handicapped people live in an independent living environment as described. This booklet will (1) *help you understand the different categories of disability requiring PCA's* (2) *describe interviewing techniques and where to look for possible jobs,* (3) *point out possible pitfalls and conflict situations,* and (4) *tell you how you can improve your communication with a disabled person.* This booklet will not focus on the tasks that you might do for a disabled person in your role as a PCA. This information can be found in other publications (see RESOURCES). Additionally, every handicapped individual has his own routine and ways of doing tasks so that it is better not to become too set in doing something only one way.

ABOUT DISABILITY

This section will be general rather than specific since entire textbooks can be written about each type of disabling condition. Disability can affect people at any age from infants to adults and senior citizens. It affects people in all income brackets from poor to wealthy. It doesn't care whether you are male or female. It doesn't matter where you live, in a small town, a large city, or on the other side of the world. Because disability is not picky about who it strikes, there are all kinds of people who are handicapped—tall people, short people, fat people, skinny people, people who are happy, sad, and in-between. Some handicapped people might become your best friend while others you might want to avoid. The point is that disabled people are individuals with different personalities and with different wants and needs. A handicapped individual is a person first.

There are two major categories of disability that we will look at briefly: 1) *congenital disability* and 2) *acquired disability from injury or disease.*

CONGENITAL DISABILITY

Congenital disabilities are those that occur at birth. It can be a birth defect such as spina bifida or cerebral palsy which can be detected at birth or which can manifest itself later in life. Disabled people who grow up with their handicap might have missed out on some experiences in their childhood causing them to be less skilled in some areas than their able-bodied counterparts. For example, some handicapped people in this group do not know how to relate to able-bodied people because they might have attended special schools where they were around only other children with handicaps. Often, children in this category are overprotected by their families; they might not have had the opportunity to make decisions or to learn appropriate behavior in public. If someone else made all their decisions for them, these disabled people might have had difficulty making choices or handling routine money matters. For example, the disabled person might not know how to choose his own clothes or how to make a deposit and use checking services at a bank.

Of course, there are some children who have grown up with congenital disabilities who are well-adjusted and who are quite capable of making good decisions and managing their own lives. These children more than likely had parents who allowed them to take risks and to participate in a variety of everyday, common experiences. For example, the parents might have taken the disabled child on shopping trips for clothes or groceries; the disabled child would probably have been included in family outings to restaurants and movies. Through this participation the child would learn how to behave in public and how to deal with able-bodied people.

ACQUIRED DISABILITY

Acquired disabilities can occur at any time in an individual's life. These disabilities can be caused by disease such as multiple sclerosis which usually affects young adults. Acquired disabilities can also be caused by a traumatic injury from an accident. The most common accidents which are responsible for handicaps are automobile accidents, diving accidents, gunshot wounds, and sports accidents. If the accident affects the spinal cord, it is called a spinal cord injury. Sometimes accidents cause damage to certain parts of the brain, and this is called a head injury. Both spinal cord injuries and head injuries affect people in different ways. For example, people with spinal cord injuries often lose sensation or feeling over certain parts of their body. In contrast, people with cerebral palsy (a congenital disability) do not lose sensation but they do lose the ability to control certain muscles; this causes them to jerk involuntarily and is called spastic movement. Head injuries are often associated with loss of memory, lack of coordination, and speech difficulties. Another type of acquired disability is amputation or loss of a limb.

Since acquired disabilities can happen at any time in a person's life, adjustment is an important process. Some people learn quickly to make the best of the situation and to go on with their lives. Others sink into a depression that might last months or even years. Every person reacts differently to a personal disability. The disability affects not only the individual but also has an impact on family and friends. If the person is married at the time of the injury, the disability affects the able-bodied husband or wife and children as well.

As a personal care attendant, it is important that you do not prejudge a person with a disability nor assume that you know everything there is to know about any single disability. As pointed out, every person with a handicap is an individual who has different physical needs and who responds to the disability in different ways. Too often able-bodied people judge a handicapped person by someone else they know who has a similar disability. For example, if you know someone with a disability and you like that person, you might have a tendency to have good feelings towards all handicapped people. On the other hand, if you know a handicapped person that you do not like, you might try to avoid all handicapped people. Both of these attitudes and approaches are a mistake. Just as in all relationships you should give the other person a chance by getting to know him or her before deciding whether or not you like that person. Even if you decide you do not personally like someone, you could still provide services to the individual, depending on your values and your tolerance level.

EQUIPMENT AND DEVICES

Depending upon the severity of the disability, various equipment and devices enable a handicapped person to function in day-to-day activities. Probably the most familiar piece of equipment is the wheelchair. There are two types of wheelchairs—manual and electric. The manual wheelchair is self-propelled by either the handicapped individual or someone else who pushes the chair. An electric wheelchair is propelled by battery-operated motors and is maneuvered by pushing or pulling a "joystick." The "joystick" can be moved with the wrist and hand motions or through a chin control for people who cannot move their hands. Some people in wheelchairs also depend upon portable respirators to assist them with breathing. Still others sit on special cushions to reduce pressure on sensitive skin areas. Some handicapped people use reciprocals or hand splints to help them hold a fork or a pencil when they cannot grip with their thumb and forefinger. Many people with spinal cord injuries lose their ability to control their bowel and bladder functions; they rely on a catheter to drain urine into a special bag usually attached to the individual's leg. Handicapped people with speech disorders might depend upon a message board or an electric typewriter to communicate with others. They may use a mouthstick to type or turn the pages of a book. All of this is to say that there are all kinds of equipment and devices that handicapped people use regularly. Each item has a specific function. The handicapped person you are working for should be able to explain the equipment and devices he/she uses regularly. For some general definitions, see the **Appendix** at the back of this booklet.

TYPES OF ATTENDANT CARE SYSTEMS

Handicapped people live in a variety of settings where they are able to take advantage of attendant care services. There are two basic types of services: (1) *private* and (2) *shared* attendant services.

(1) *Private Attendant Services*

Private attendant services are when one attendant works for only one handicapped individual. The PCA might work in the disabled person's home or apartment or the PCA might live with the disabled person, for example, in a college dormitory room. The handicapped person might live alone, with parents, or with husband or wife. In all cases, the disabled individual is generally responsible for hiring, supervising and terminating his own PCA.

(2) *Shared Attendant Services*

In many of the larger communities, groups of handicapped people with similar attendant needs will live close to each other (for instance, in the same apartment complex). Attendant services can then be provided to the entire group so that the group "shares" PCA's. In this situation, one or two PCA's are available throughout the day or night. This means that you might work an 8-hour shift where you are "on-call" during the entire shift. You would provide services to everyone in the group, not just to one person as in the private attendant situation. Most shared attendant service systems hire a person called the Attendant Manager who is responsible for scheduling and supervising the PCA's. The handicapped people who live in a shared attendant service system usually share the responsibility of hiring and terminating PCA's.

LOOKING FOR A JOB AS A PERSONAL CARE ATTENDANT (PCA)

The independent living movement is quickly accelerating and along with it is the rising need for personal care attendants (PCA's). There are several ways to look for a job as a PCA. The need is particularly great in a large city where groups of handicapped people may live near each other as described above. There is also much opportunity for working with individuals rather than with groups both in large and small communities. The following list will give you some idea about where to start inquiring about potential PCA jobs.

1) **State Department of Vocational Rehabilitation**—This state agency has both local and regional offices in every state. The agency provides counseling and support services to disabled people. Counselors in this agency often know disabled people who need attendant care services.

2) **Rehabilitation Hospitals**—General hospitals sometimes have rehabilitation floors for treating traumatically injured patients. There are also entire hospitals dedicated to the rehabilitation of handicapped people (for example, The Institute for Rehabilitation and Research in Houston, Texas). A good place to get leads on handicapped people who might be looking for attendant care is the Social Service departments of such hospitals.

3) **Rehabilitation Facilities**—Rehabilitation facilities provide services to handicapped people but are not hospitals. Rehabilitation facilities include such agencies as Easter Seals or United Cerebral Palsy associations. Contact the social worker or the director of these agencies when you look for a job as a PCA.

4) **Consumer Organizations**—These are clubs or organizations where handicapped people get together to talk about their concerns, plan projects to improve accessibility in their community, and participate in recreational activities. What better place to advertise your services than among those people who could use them!

5) **Independent Living Centers**—Independent Living Centers are becoming popular across the country. These are "agencies" which provide non-traditional, coordinated services to handicapped people such as peer counseling, transportation, and referral and information about attendant care, housing and other services. Find out if there is an Independent Living Center in your area and list your abilities and services with them. Some Independent Living Centers provide housing facilities for handicapped people, and might operate their own attendant service systems.

6) **Newsletters**—Most of the sources mentioned circulate their own newsletter. Ask if you can put a "Position Wanted" ad in their publications. Your ad might read something like:

> WANTED: seeking full-time position as a personal care attendant for a physically handicapped person. Call Jim at 000-0000.

The purposes of the job interview are to talk about the specifics of the job and to try to figure out from a face-to-face meeting if the two of you can get along. Traditionally, the job interview is controlled by the person who is doing the hiring; in this case, however, it is important to ask questions, too. This is because the job relationship is particularly close in this type of situation since you will be assisting the handicapped individual with such personal tasks as dressing, showering and other grooming activities. Again, every handicapped person is an individual and will need different kinds of assistance. Be able to tell the disabled person why you want the job, and also, know what your limits are.

In the actual interview there are several areas you will want to cover:

1) **Find out the hours you will be working.** Is it a split shift for some individual or would you be "on-call" for an 8 hour shift? Sometimes handicapped people only need assistance during peak hours, that is, during the early morning and evening hours when people are getting up and dressed for the day and then getting ready for bed in the evening. In this case you would be working a split shift. Other handicapped people need help consistently throughout the day so that you would be working a full 8 hours.

2) **What days will you be working? Are you willing to work on any weekends?** Unfortunately, the need for physical assistance does not just happen Monday through Fridays. It is unreasonable for the handicapped person to expect you to work 7 days per week, so be sure you know when you would have days off. Even if you are interviewing for a live-in position (that is, a situation where you would live with the handicapped person), you should arrange to get time off regularly.

3) **Find out exactly what the disabled person expects you to do as a PCA.** You should also be aware of what you are willing to do. For example, will you perform housekeeping and cooking chores? What about driving the handicapped person to school or work? Personal care activities have already been mentioned as a part of the PCA's responsibilities and include areas such as dressing, showering, bowel and bladder care, etc. Although these duties might be difficult for both of you to talk about, it is a necessity. The best way to approach these personal issues is in a matter-of-fact way. Think about how you would feel if you were not able to dress yourself or if you needed help in the bathroom. The handicapped person who is looking for a PCA has probably accepted the fact that he/she needs such assistance but might feel uncomfortable when talking about these personal needs (such as bowel and bladder care). However, you need to know exactly what these duties are so that you will be able to make a good decision about accepting the job. One way to avoid future misunderstandings about the job is to draw up a contract or a list of duties, responsibilities, and expectations.

4) **Personality is an important issue.** Can you work with someone who is bossy or demanding? What about someone who is shy and withdrawn and won't tell you what they want you to do? For more characteristics to look for, see the section on **The Relationship Between the PCA and the Handicapped Individual.**

5) **What is the rate of pay and how often will you get paid—once a week, once a month, etc.?** Who will pay you—the handicapped person or a third party payer? Will there be a lag time between the time you start work and your first paycheck? Will you need to fill out any special forms to get your money?

These are just a few of the areas that need to be covered during the interview. You will probably think of other questions as you talk with the handicapped person. Getting the answers will help you make wise decisions and will help create a good job atmosphere where both of you can benefit.

TRAINING

The handicapped person you are working for will probably want to train you personally since he/she will know about any special needs and will be able to tell you about his/her normal daily routines. Remember, these routines will be different for each handicapped individual so that it is important that you do not make assumptions about how someone should or should not perform activities of daily living. It is usually the responsibility of the handicapped person to tell you how to do a task such as how to help him/her transfer from the bed to the wheelchair. The first few days on the job the handicapped person might ask someone who is familiar with his needs to be present in order to show you how to do some jobs. This person might be a family member or an experienced PCA who has worked with the handicapped person before.

If a formal training program is available, the handicapped individual might want you to enroll. For example, in Houston, Texas, the Attendant Training, Referral and Information Project (ATRIP) offers a 50 hour class for PCA's through the Houston Community College. Other training programs might be offered through rehabilitation hospitals or group living situations as discussed earlier under **Types of Attendant Systems.** Many handicapped people prefer on-the-job training and rely on formal training programs to help PCA's become familiar with words (see **Appendix**) and general techniques they might not know about.

One important area you should ask about early in the job is what to do in case of an emergency. In general, there are two types of emergency situations. One type is a routine emergency such as a deep cut or a fall. For a routine emergency you will need to know regular first-aid procedures. The other type of emergency is one that is directly associated with a particular disability. For example, if you are working for a person with a spinal cord injury, you should know what to do if he/she gets dysreflexia. If you work with a person who has a head injury, you should know something about seizures. How do you find out what kinds of things to look for? Ask the person you are working for! Also, make sure you have the names and phone numbers of the handicapped person's doctor, pharmacy, closest relative or friend, an ambulance service and the fire department. It pays to be prepared.

THE RELATIONSHIP BETWEEN THE PCA AND THE HANDICAPPED PERSON

In any kind of job there is a relationship, good or bad or neutral, between you and your supervisor and co-workers. When providing attendant care services, you will naturally form a relationship with the handicapped person you are working for. You will like him or not like him or you might have feelings that are somewhere in-between liking and not liking (that is, neutral feelings). The kind of working relationship you have with the handicapped person will depend upon both of your personalities and communication styles. There will be anxiety and tension in some relationships because no two people like exactly the same things; this can cause disagreements or conflict. Another factor that affects relationships is motives. A motive is the reason you do something in a particular way. For example, you might rush through a job task because another person is waiting for you; the person that is waiting motivates you to hurry. Some motives are hidden, that is, you don't know why you do something one way when there are other ways of doing it. The motive is still there, though. The handicapped person will interact with you in certain ways because of his/her own motives. Being aware of the motives for your actions and knowing your own values will help you evaluate your abilities to get along with and to work for a variety of people.

The following character types will illustrate some traits you might recognize in handicapped people, your family and friends, or even yourself. No one behaves in any one way but might act different ways with different people and in different situations. There are many reasons you behave in a certain way at any given time including the way you feel, problems you're worried about, the weather, or impressions you hope to make. The following illustrations are a variety of behaviors with the possible results or consequences of each.

Disability Character Types

1) **The AGGRESSOR:** these individuals are characterized by being overly demanding and bossy. They show no appreciation to the attendant.

2) **The MARTYR:** this individual's favorite phrase is "Don't worry about me," followed by a big sigh. This attitude encourages feelings of pity and even guilt from the attendant.

3) **The PACIFIST:** this is a passive personality whose main goal is to avoid conflict. This often results in unmet needs because of a fear that the attendant might be angry if asked to perform a task outside the normal routine.

4) **The GUILT-MAKER:** these people have difficulty accepting their disability and attempt to place the blame on others. Their non-verbal message is "Oh, poor me" or "The world owes something to me." Because no one wants to accept the blame or the negative messages from the GUILT-MAKER, there is a tendency to avoid this type of person.

5) **The ROLLERCOASTER:** these people experience extreme mood swings which cause their behavior to be inconsistent. One minute this person is happy, the next, sad. Not knowing what to expect can hinder effective communication.

6) **The DRUG ABUSER:** the handicapped person might behave in an inconsistent manner and/or be unable to assume responsibility for his own care. This puts the burden of care on someone else and is not conducive to the idea of self-direction in independent living.

7) **The PREACHER:** the disabled individual attempts to convert the attendant to accept his/her religious values, interspersing his conversation with quotes from the Bible or other religious doctrine. This person does not respect another person's rights to their own beliefs and values.

8) **The PERFECTIONIST:** these individuals are often described as "picky" by their attendants. Generally, the handicapped person insists that tasks be performed in very specific, detailed ways with no flexibility. Setting realistic priorities might be difficult for this disabled individual.

9) **The ASSERTIVE PERSONALITY:** assertive handicapped people are able to express their needs in a direct yet non-threatening manner. They do not manipulate other people. They know themselves and usually have an air of self-assurance.

Attendant Character Types

1) **The NURSE:** these are people who have developed their own medical techniques and refuse to do a task any other way. They direct the handicapped person's care rather than the disabled person assuming responsibility for his/her own care.

2) **The "MOTHER":** The attendants feel their job is to take care of disabled people and to nurture them. This is the type of person who hovers sweetly, pats disabled people on the head or arm, and does things that are not needed.

3) **The BEST FRIEND/COMPANION:** the attendant allows no privacy for the handicapped person and refuses to allow him/her to have other social relationships. This attendant would probably expect to be included in all social activities planned by the disabled individual and indeed, would be hurt if left out.

4) **The OVERPROTECTOR:** this person's creed is "I know what's best for you." The attendant might try to prevent the handicapped person from taking even minor risks, thus encouraging a dependent relationship.

5) **The GOOD SAMARITAN:** the attendant is a "do-gooder" whose primary objective is to make himself/herself feel needed. This person's creed might be "You've suffered enough already, let me take care of you." The GOOD SAMARITAN will do more for the handicapped person than is necessary and may treat him/her like a child.

6) **The DRUG ABUSER:** these attendants may do a good job when they are not "spaced out." They are usually unreliable and/or inconsistent in behavior.

7) **The PREACHER:** these individuals insist upon imposing their religious beliefs upon the handicapped individual. Some attendants have reportedly attempted to perform their duties through prayer. They do not respect another person's right to his own beliefs and values.

8) **The ASSERTIVE PERSONALITY:** like assertive handicapped people, these attendants state their feelings and needs in a direct yet non-threatening manner. They do not "put down" another person. They behave in a consistent manner and have a strong sense of self.

Many more behaviors could be added to each list. If you take one character type from each list, you can see that a particular kind of relationship might develop. Some of these relationships will contain conflict while others will be satisfying to both of you.

No matter how good the relationship there will probably be some conflicts which happen at specific times because of specific incidents. These are called situational conflicts. An example of a situational conflict is:

A handicapped woman asks her PCA to stay an extra hour to help her cook her dinner. The PCA has other plans for the evening and besides, cooking was not a duty agreed upon in the job interview.

Situational conflicts can occur at any time during the day-to-day relationship with the handicapped individual.

Another example of a situational conflict is:

A disabled person requests to go to bed later than his attendant who shares his apartment.

How do you resolve these conflicts? Each person's response to a conflict situation is important. There are three basic ways to respond to any situation: (1) **the passive response,** (2) **the aggressive response,** and (3) **the assertive response.** These response patterns and their consequences can best be illustrated using the two examples of situational conflicts above.

Situation A: *A handicapped woman asks her PCA to stay an extra hour to help her cook dinner. The PCA has other plans for the evening and besides, cooking was not a duty agreed upon in the job interview.*

1) **Passive response**—The PCA stays the extra hour and does not mention his/her own plans. **Consequence:** the PCA feels angry and resentful and might take it out on the handicapped person in other ways.

2) **Aggressive response**—The PCA "blows up" at the handicapped person, yelling that cooking isn't one of the responsibilities agreed upon. In the outburst the PCA might also complain about other grievances. **Consequence:** the handicapped person might retaliate with anger or feel hurt, defensive and humiliated. The PCA storms out without completing his/her regular duties.

3) **Assertive response**—The PCA tells the handicapped person about his/her other plans gently but firmly and reminds the handicapped woman that cooking was not one of the PCA's duties. **Consequence:** The handicapped woman understands that her PCA has other plans. If cooking is going to be an on-going need there is room here for discussion and perhaps a compromise can be reached. Communication has not been cut off and there are no misunderstandings or hidden grievances.

Situation B: *A disabled person requests to go to bed later than his attendant who shares his apartment.*

1) **Passive response**—The PCA remains awake to help the disabled person go to bed when the disabled person wants to. **Consequence:** the PCA feels anger and resentment towards the handicapped person who has not discussed his reasons for wanting to go to bed earlier. The handicapped person may be unaware that there is a problem.

2) **Aggressive response**—The PCA becomes angry and says he doesn't care what time the handicapped person wants to go to bed. The PCA berates his roommate for not caring about his needs. **Consequence:** the handicapped person is angry because the PCA has not considered his needs. The PCA might force the disabled person to do it his way and therefore, cause further resentment and anger. There is no room for discussion.

3) **Assertive response**—The PCA explains his need to go to bed earlier. **Consequence:** They agree to perform most of their nightly routine early in the evening. The handicapped person gets to stay up later and the actual process of going to bed will take a minimal amount of time. The PCA can go to bed whenever he wants. Through compromise both the handicapped individual and the PCA get their needs met. No one's feelings are hurt.

As you can see, not only is it important that you understand your needs but it is equally important that you understand the handicapped person's needs. The assertive response is the most honest way of dealing with conflict situations; using assertiveness can lead to effective compromises where each person involved contributes and is comfortable with the resulting solution. Open and direct communication will facilitate understanding but is not guaranteed to get you what you want. Being an assertive person takes practice. Remember that you can only control and be responsible for your own responses.

In any relationship it is important to project what the possible consequences of your actions are. Sometimes you may respond passively or choose to ignore a comment or action because the end result is not that important to you. For example, does it really matter to you that the handicapped person sleeps till noon and you think he/she should be up and doing something? On the other hand, there may be times when you feel so strongly about a situation that you might be willing to risk damaging the relationship in order to defend your values. For instance, suppose the handicapped person wants you to help him/her smoke marijuana and you don't want anything to do with it. Are you willing to risk losing your job by being aggressive about your feelings concerning this matter? Your response to any situation is an individual choice. Each set of actions will require individual consideration and evaluation.

BACK-UP SYSTEMS

There will be times when you will not be able to get to work for some reason. You might become ill, develop transportation problems, get weathered in, or experience some other type of emergency. Whenever possible you should give the handicapped person adequate notice (that is, several hours or days in advance) that you will not be able to work on a particular day. It is the handicapped person's responsibility to find a substitute. However, if you know someone who might be able to work for you in your absence, talk it over with the disabled person. He/she will appreciate your thoughtfulness.

The same principles apply when you want to leave the job permanently. Try to give the handicapped person at least two weeks notice that you will be leaving and explain why. A month's notice is even better since it might take some time to locate and hire another PCA. The handicapped person might also want you to be available to help train the next PCA.

Rewards

The job of PCA can be a very rewarding experience. There is a potential for developing some deep, personal friendships. Awareness of disability is an inherent part of the job. And there are few professions that allow you to have a direct effect on the quality of life of another human being. The job of personal care attendant offers you this unique opportunity.

Appendix

TERMINOLOGY

Acquired disability—a disability resulting from injury or disease.

Catheter—a tube which drains urine from the bladder into a drainage bag.

Chucks—disposable, plastic pads that may be used to protect bedding during bowel elimination programs.

Communication board—letters of the alphabet and/or simple phrases are printed on a board; a disabled person with communications problems can point to these letters or phrases to communicate with another person.

Congenital disability—a disability which occurs at birth.

Corset—a brace made of fabric with metal inserts which helps support a person's back and/or trunk.

Dysreflexia—usually signifies overextension of the bladder in people with spinal cord injury; rapid rise in blood pressure, sweating and headaches are some of the symptoms. This is an emergency situation and should be immediately attended to.

Egg-crate mattress—a foam rubber bumpy mattress which fits on top of a regular mattress; its purpose is to reduce pressure areas when lying down.

Electric wheelchair—a battery-powered, motorized wheelchair which can be operated independently by the disabled person.

Lap-board—a tray which fits onto a wheelchair, can be used as a desk, an eating surface, an exercise surface, etc.

Legbag—the urine drainage bag, usually attached to the handicapped person's leg; the catheter drains urine from the bladder into the legbag.

Manual wheelchair—a non-motorized wheelchair which can be pushed by an able-bodied person; handicapped people with upper-body strength can propel themselves in a manual wheelchair.

Mouthstick—a wooden dowel with a rubber tip; this utensil can be held in the mouth and is used to turn pages of a book, type, draw, and point to words or phrases on a communication board.

Paraplegic—a handicapped person who has lost the use of two extremities, usually his/her legs; the rest of the body functions normally except for some loss of sensation and bowel and bladder dysfunction.

Pressure sore—a skin irritation (red spots on the skin) or break caused by unrelieved pressure; if a pressure sore turns into a decubitus ulcer, or a deep, open skin "sore" it can take months to heal. To relieve pressure, weight shifts must be done periodically throughout the day.

Quad pegs—on a manual wheelchair, these are evenly-spaced extensions on the wheel rims; they are used to enable quadriplegics to push themselves since most quadriplegics cannot grip the rims.

Quadriplegic—a handicapped person who has lost the use of all four extremities to varying degrees; loss of sensation as well as bowel and bladder dysfunction usually characterize quadriplegia.

Reciprocals—braces and hand splints which aid a handicapped person in performing activities of daily living such as writing, eating, grooming, etc.

Respirator—a machine which contracts and releases the diaphragm and assists the handicapped person with breathing.

Scoliosis—curvature of the spine.

Spastic—involuntary muscle contraction which sometimes causes jerky movements; especially prevalent in persons with cerebral palsy but also occurs in persons with spinal cord injuries.

Spinal cord injury—any disability resulting from damage to the spinal cord; depending on where this damage occurs, the results could be varying degrees of paraplegia or quadriplegia.

Trapeze—a triangular shaped bar attached to the ceiling or a bar across the bed; some handicapped people can use a trapeze to help them with sitting up and with transfers.

Wheelchair cushion—a special cushion to relieve pressure on sensitive skin areas while in a sitting position.

RESOURCES

Apgar, Virginia and Joan Beck **Is My Baby All Right?** New York: Trident Press, 1972.

Attendant Training Manual, Respite Care, Cerebral Palsy Treatment Center, 1415 California St., Houston, Texas, 77006.

Attendees and Attendants, College and University Personnel Association, Suite 120, Eleven Dupont Circle, Washington, DC 20036.

Burke, D., Murray, D., **Handbook of Spinal Cord Medicine,** Raven Press, New York, 1975.

Cole, Jean A., Jane C. Sperry, Mary Ann Board, Lex Frieden **New Options** The Institute for Rehabilitation & Research, 1979.

Cole, Jean A., Jane C. Sperry, Mary Ann Board, Lex Frieden **New Options Training Manual,** The Institute for Rehabilitation & Research, 1979.

Ford, Jack and Bridget Duckworth **Physical Medicine for the Quadriplegic Patient,** F.A. David Co., 1974.

Handbook for Parapiegic and Quadripiegic Individuals, The National Spinal Cord Injury Foundation, 369 Elliot St., Newton Upper Falls, Massachusetts, 02164.

Hayes, Jim and Shannon Smith **Live-In Attendant Care Manual,** The University of Texas at Arlington, Educational Support Services Office, Arlington, Texas.

Larson, Maren R. and Daniel Snobl **Attendant Care Manual,** Southwest State University, Marshall, Minnesota, 56258.

Meyers, Julian S. **An Orientation to Chronic Disease and Disability** New York: Macmillan Company, Toronto, Ontario: Collier-Macmillan Canada, Ltd., 1965.

This is one of three booklets in a series about Independent Living and Attendant Care. The titles in the series are:

Independent Living With Attendant Care: A Guide for the Person With A Disability

Independent Living With Attendant Care: A Message to Parents of Handicapped Youth

Independent Living With Attendant Care: A Guide for the Personal Care Attendant

The content of each booklet is a result of three years experience in the New Options Transitional Living Program at The Institute for Rehabilitation and Research (TIRR), Houston, Texas. The material was gathered from New Options participants, staff associates, attendants, and families who shared their personal experiences. Each booklet is intended to be a guide with suggestions that can be adapted to each individual's situation.

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